

# *LIVING THE UNEXPECTED*

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It was October 3, 2014. I was looking forward to a well-deserved weekend off. I had plans to put together, things to do!

I awoke early that Saturday morning, made my coffee and sat in my favourite chair, mulling over what to do first. As I mindlessly reached for my mug I failed to notice that I wasn't really "feeling" the handle and consequently dropped the entire cup. I thought it wasn't anything to pay attention to. When it happened a second time and then a third, I brushed it off as a "weird thing".

I went about my day not noticing that my body was trying to get my attention. My left leg was oddly numb along the outside. Still, I dismissed it as "no big deal."

On Sunday morning I tried to get out of bed and my limbs simply would not cooperate. I managed to crawl to the living room, grabbed my phone to call my daughter and discovered that my lips couldn't form words. I literally held my mouth with my disengaged fingers to form "come help me"...and that was all I could manage.

I was rushed to emergency at Royal University Hospital in Saskatoon where I underwent inconclusive testing for the next several hours. The question came up at one point as to whether or not I had had a flu shot recently. No, I had not, so the next step was a neurology specialist coming in to do a spinal tap. (Apparently it was really cool to watch!)

I remember little after that. I deteriorated within hours as my body shut down and the raw nerve pain took over. The decision was made on Tuesday, October 7, to induce me into a coma.

Due to the ferocity of the breakdown, my organs began to malfunction and 3 emergency drains were implanted into my abdomen. I'd developed an abscess in my stomach. Unfortunately, during the procedure damage was done at the valve site between my small and large intestine causing it to rupture. On October 23rd I had to undergo another emergency surgery to rectify this. The surgeon had to take out quite a length of both my small and large intestine and fit me with an ileostomy.

Ten days before Christmas I woke up. There were somewhere in the neighbourhood of 16 lines coming out of my body, my eyes were sutured shut, I was completely paralyzed and in excruciating pain.

The next 6 weeks of existence were a blur of my children's panicked faces, the terror and relief in my mom's eyes, my Daddy's tears, hushed voices of my closest truest friends, my confusion and utter fear. I was trapped inside myself. Communication was nearly impossible.

I was moved to an observation unit and began what would be the utmost fight of my life. Physiotherapy began, relearning basic skills such as blinking and swallowing. Oh, the disappointment of missing Christmas dinner!

I spent the next weeks coming to grips with what I was. Invalid. Invalid. Broken. Never to be normal again. Yet, my spirit would not allow me to wallow. I knew I had a choice to make: the whole

“bitter/better” thing. And even in its muddled state my mind was still capable of basic thought. I knew I wasn’t giving in to this! It Would Not Win!

In February of the following year I was well enough to be transferred to Saskatoon City Hospital to begin rehabilitation.

After four months of intense, aggressive and seemingly impossible learning, pushing, failing and “giving myself one more try” I was able to go home with a walker.

Due to the rapid onset of my symptoms I had been diagnosed with GBS, which often follows such a course of sudden paralysis and gradual recovery. However, that was a mistake.

Two months later, I relapsed and was rushed back to emergency, back in a wheelchair. With my fabulous medical team on board, they quickly determined that a new diagnosis was required. And CIDP emerged into my vocabulary. (It took me a whole year to get my mouth around “demyelination”).

Now that we were on the right track in terms of my medication and the introduction of the IVIG treatment process, the rehabilitation was rapid and I was back home in less than 2 months. But that’s where the real work began. What to do with what I had left? My mind, relationships, life. The stuff that mattered.

It has been quite a ride. And although nothing is as it was, I am utterly grateful for each step, each bit of progress as well as the setbacks. The struggle remains: my crippled feet, my un-cooperative hands, the gaps in cognition. The pain is always there. Yet, I’m thankful. Thankful for my family, my children, my tribe of cheerleaders who have stood by as I tackle living.

It will be four years this October. Four years through the refiners’ fires of CIDP. 4 years of the worst and best days imaginable. And yet, I feel truly blessed. My health crisis has given me the opportunity to reach out and open doors to encourage and support others as they struggle. I value every difficult day as it encourages me to be mindful of what matters most. Life is no longer “normal”, but who wants that?!